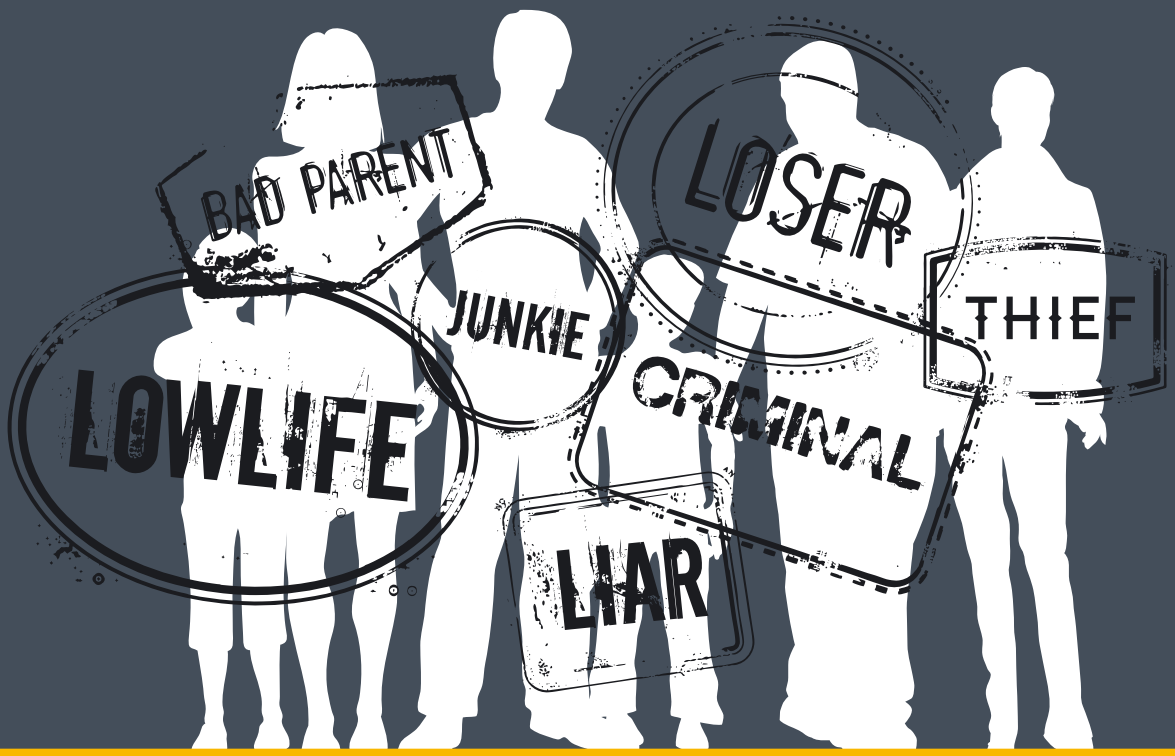
Challenging Stigma

Tackling the prejudice experienced by the families of drug and alcohol users



Adfam

Families, drugs and alcohol

Funded by an educational grant from Reckitt Benckiser Pharmaceuticals Ltd.

Foreword

Stigma and drug use have been associated for a long time. They have also been popular topics of debate in recent years and the focus of a growing body of research. But in the same way that families have often been absent in other drug policy discussions, their perspective on stigma is much less widely researched. We hope this report will help shine a light on families' experiences.

Often, regardless of their own behaviour, families find themselves defined by the 'addict' label attributed to their drug using relatives. And this doesn't just apply to parents: children, siblings and partners are also heavily stigmatised, as you'll read in this report. It's also not just about the media, or the gossiping neighbour: it comes from previously close friends, colleagues at work and even other relatives.

There is often no way for families to avoid being stigmatised; even if they're completely disengaged from the drug user, the label of addiction can still be attached to them. At the other end of the spectrum, families who support the user day in, day out can be derided as foolish for standing by them despite their behaviour.

At Adfam we've been talking about the need to reduce the isolation of families affected by drugs and alcohol for almost thirty years. Telling families 'you're not alone' is a key aim of many family support services, but so many are still feeling precisely that: alone. Upsetting though they may be, we hope that the experiences recounted in this report will resonate with families out there who still suffer in silence.

It's time to change the public perception of families affected by drug and alcohol use. The best way to combat stigma is to take the issues out in the open, not hide them away. By talking about it candidly, we hope to create a groundswell that counters the blame and guilt weighing so many families down.

Families who don't feel stigmatised would be more likely to seek support for their own needs, and more able to take an active role in their loved one's recovery if they choose to do so. Families need their own 'recovery movement' which brings them together, illustrates their experiences in their own words, and celebrates the courage it takes to access support. We hope this report will prove an asset to this cause.

Vivienne Evans OBE
Chief Executive, Adfam
July 2012

Aims of this report

- Improve awareness and understanding of how stigma affects family members of drug and alcohol users, and drug and alcohol users themselves
- Codify existing literature around the topic and provide additional, emotive, person-centred perspectives
- Create a successful platform through which to engage with multiple stakeholder groups around the stigma experienced by drug and alcohol users and their families

Scope

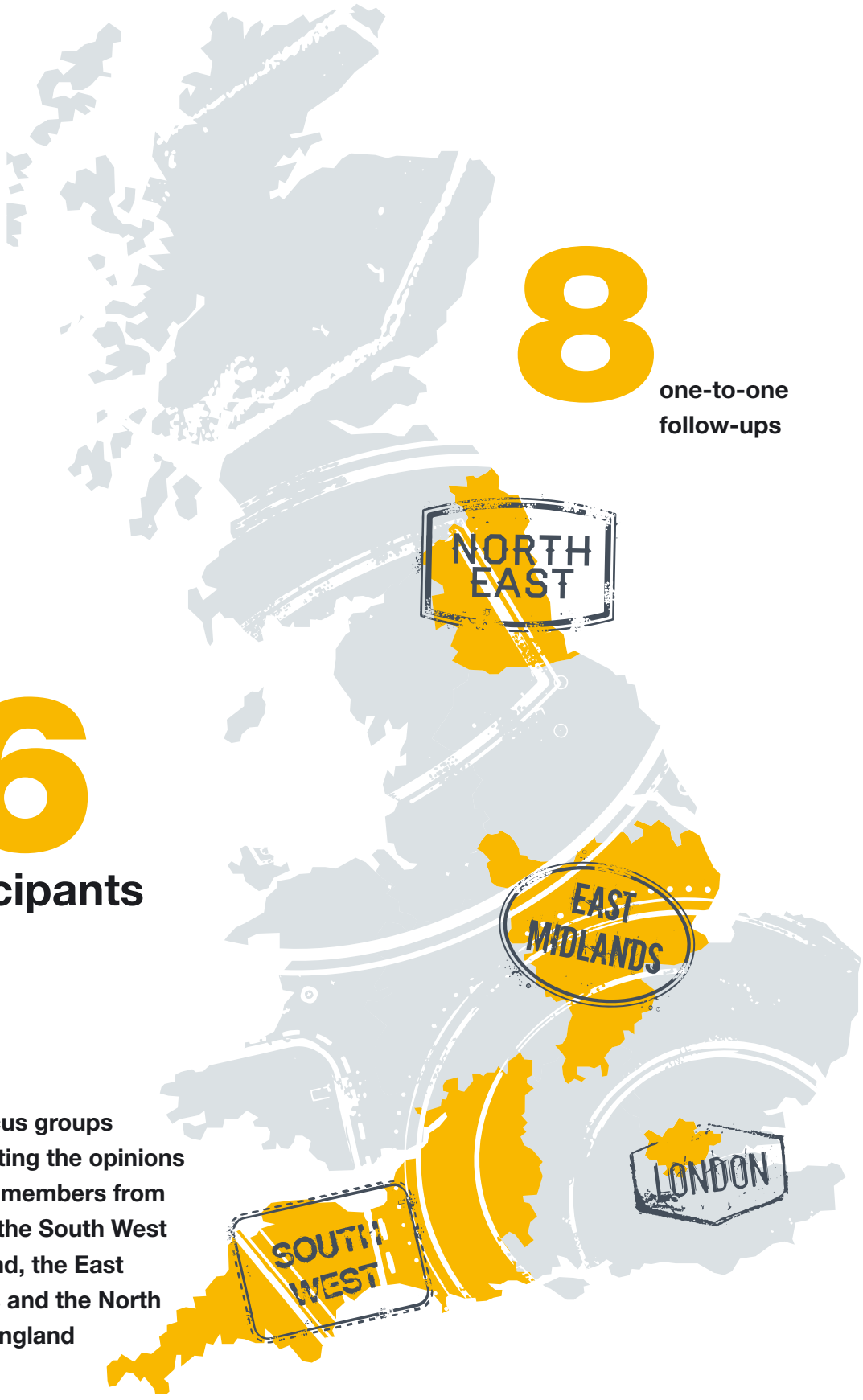
- Families often struggle to express themselves regarding someone else's substance use due to fear of stigma and concern that they won't be properly understood
- Families of drug and alcohol users need support too, and in many cases experience stigma on a daily basis
- Substance users and their families should be seen as part of a whole family unit, not separately
- The focus of this research is on stigma associated with illicit drug users and their families, but parallels can be drawn with families affected by problematic alcohol use

In order to effectively capture relevant and topical perceptions of stigma, and to ensure existing research and academic thinking resonates with real world experiences, Adfam conducted a series of focus group sessions and one-to-one follow-ups with families affected by substance use. Their opinions, insights and experiences have helped shape this report and have been included to illustrate the real-life impact of stigma.

FOCUS GROUP SESSIONS

8

one-to-one follow-ups



36

participants

4

focus groups representing the opinions of family members from London, the South West of England, the East Midlands and the North East of England

Scale and scope of original qualitative research

What do we mean by stigma?

According to the Oxford English Dictionary definition, stigma is generally said to be:

"a mark of disgrace or infamy; a sign of severe censure or condemnation, regarded as impressed on a person or thing; a 'brand'."

Stigmatisation occurs when a person possesses an attribute or status that makes them less acceptable in the eyes of other people, thereby affecting the way others interact with them. For drug and alcohol users and their families the stigma associated with addiction can even become a 'master status' by taking centre stage and obscuring the other elements of a person's character and identity.

Families affected by substance misuse describe how stigma has personally affected them:

"Stigma for me meant being treated differently once people knew of my son's drug use."
{Lincoln}
"...because there's a drug user or an alcoholic in the family, a lot of services think the whole family's the same so you're all judged on that person's behaviour or that person's lifestyle... and quite often your reaction to the user's lifestyle is judged as well."
{Newcastle}
"Labelled with a big invisible sign that I can't see but others can."
{Lambeth}
"I just want to cry at hearing the word 'stigma' – it's that powerful."
{Somerset}

As well as this externally imposed 'stigma by association', the high levels of guilt and self-blame experienced by the families of drug and alcohol users, particularly parents who believe that the upbringing they provided is responsible for the substance misuse, mean that some families effectively stigmatise themselves through feelings of guilt and low self-worth. This experience of stigma as a result of a relationship with, or proximity to, a stigmatised person is described by 20th century sociologist and writer Erving Goffman in his seminal work on stigma and is known as 'courtesy stigma'[1].

What research tells us

> "I got people saying *'oh, you must be a low life because why would you want to be with a heroin addict?'.*"
> {Lambeth}

We know that millions of people are involved every day in the care and support of people trying to turn around their lives; many of them give this care with little in return despite the significant harms done to them as a result. A UK Drug Policy Commission (UKDPC) study suggests that around **1.5 million people** in the UK are significantly affected by a relative's drug use[2], whilst other studies have suggested this number is nearer to **8 million**[3]. The UKDPC also asserts that families can experience harms resulting from drug dependence worth **£1.8 billion per year**, for example through healthcare costs, lost employment opportunities and theft, and provide unpaid care that saves the state up to **£750 million** annually[2].

A DrugScope/ICM poll found that **19%** of people have had either personal experience of someone's addiction or they know someone in their family or network of friends who has[4]. For a substantial number of people, therefore, attitudes to problem drug users are informed by first-hand experience rather than just indirect sources such as the media; ***so why is it that people who use illicit drugs are among the most stigmatised groups in our society?***[5,6,7]

In 2010, a large UK-wide survey of public attitudes towards drug users was carried out and the results were compared with views about people with mental health problems, another historically stigmatised group. The results are summarised opposite:[8]

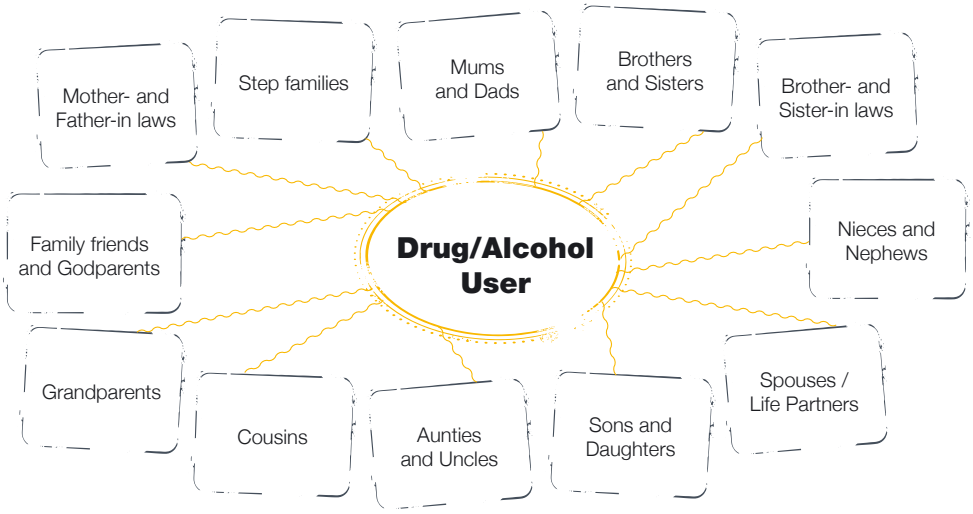
- When questioned about living next door to a person with a mental illness, only **9%** of people said they would not want to. This figure rises to **43%** when the neighbour in question has a history of drug dependence.
- **93%** of people think that those with a mental illness deserve the best possible care, but only **68%** think the same about people with a drug dependence.
- **58%** of people think one of the main causes of drug dependence is lack of self-discipline and willpower.
- Only **5%** of people think that people with a mental illness 'do not deserve our sympathy', but **22%** took this view towards people with a drug dependence.
- **60%** of people view drug dependence as a 'chronic illness', although this percentage is higher (**80%**) when discussing mental illness.

The same research included two attitude statements about stigma towards family members of people with drug dependence and found that:

- **23%** of people believe that most people would not become dependent on drugs if they had good parents.
- **One in three** people agreed that parents would be foolish to let their children play with the children of a person with a history of drug dependence.

Research suggests that people stigmatise not only the person with a history of drug dependence but also, by association, their family members.

Who do we mean by the whole family?



Families are undoubtedly negatively impacted by their loved one's substance use. Stigma experienced by family members of people with drug problems can dramatically alter their day-to-day lives in a multitude of ways: social invitations dry up, children are targeted by bullies, friends and family withdraw their trust around money, and colleagues at work can treat them differently.

"The impact of a person's drug use can have a negative impact on the family member's social life, leading to increasing isolation, which may be exacerbated by the feelings of guilt and shame that families often feel."[9]

"If I go into a sterile environment where nobody else has drug use in the family, publicly, and I let slip that my son is a drug user you can immediately hear the change in the conversation... ***"Oh it must be terrible"*** but then they start to treat me differently. The classic is the handbag, the handbag is moved; I'm a risk. They see me as a threat, thinking I might steal for my son."

{Lincoln}

When someone in their family uses drugs or alcohol, people can experience anger, betrayal, guilt, fear, isolation and loss of control. Family members can be abandoned by their friends and relations, sometimes as a result of their continued support for the drug user, and find themselves isolated from the support they need themselves.

Isolation

Moira describes the recent upheaval in her life since discovering her husband's long-term habit:

> "I've stopped going out and communicating with anyone, and ***I can't mention his name to my family*** as it's like mud. They probably think I'm an idiot and they're worried I'm going to become untrustworthy."
>
> {Somerset}

Debbie, who lives with her husband's addiction, says of her experience:

> "***the worst thing about stigma is the isolation*** – if it wasn't for the stigma people would get help easier and quicker. I had absolutely nobody to talk to about it and then I started volunteering at drug and alcohol services and could tell my story… being able to talk about it was such a relief."
>
> {Lincoln}

Family members, such as parents, may blame themselves for not preventing their relative's drug dependence and feel shame and embarrassment. Subsequently, they may avoid other people and conceal their relative's situation for fear of negative reactions and stigmatisation.

Concealment

As Brenda says of her daughter's drug addiction:

> "***I didn't want anyone else to know;*** I kept it hidden from everybody as I wanted them to be proud of my daughter and think she was doing good things in her life. So for eleven years I let my mum believe she was clean."
>
> {Lambeth}

> "***I dressed my children immaculately*** so people could see they were well looked after. I dressed myself immaculately. ***It was almost as if I was wearing this kind of mask.***"
>
> {Lincoln}

Permanence

> "Once it's there you can't get rid of it; in all areas of my life I've experienced it."
>
> {Somerset}

> "It's hard for her, ***she's still labelled with names like 'crack-head'***, but she's a human being; she's trying hard to get on with her life. She got her kids back; got married again."
>
> {Lambeth}

Families feel that, once it has been established, the label of stigma is impossible to remove regardless of their own behaviour or that of the substance user. Every family is different and their responses can vary widely from dedicated and long-term support to 'tough love', disengagement, and everything in between. But whether families disengage from the drug and alcohol user or go to great lengths to support them, and regardless of whether the substance user is in recovery or not, stigma is still reported as inescapable. They can be drawn into the secrecy and story-telling that surrounds drug dependence, and may live with other people's insults, abuse and discrimination. Brenda tells of the dangers she risked to protect her daughter:

> "I actually would go to some of these crack-houses looking for her… but you don't care, you just want your daughter out of there. I was threatened but ***you have to face up to things***, you don't think about it at the time, 'cause it's your child."
>
> {Lambeth}

Helen also tells of the extent she was prepared to go to support her son:

> "***I would go and buy his drugs***, go and see the dealers; I would go and do all that."
>
> {Lincoln}

Clearly then, drug use doesn't just affect individuals: families are also at the frontline of addiction. They experience stigma whether or not their family member is in recovery, and regardless of what their own approach has been to dealing with addiction in the family.

The family and recovery

Evidence shows that treatment is more likely to be effective, and recovery to be sustained, where families, partners and carers are closely involved.[10]

Supportive relationships with others are a key element in successful recovery from drug or alcohol dependence and a happy family life is a vital aspiration. From the start, a drug-dependent person must have determination, resilience and faith in reaching their goal: to change and to leave their past behaviours. Yet recovery is a journey: a long, non-linear process with many potential hurdles, setbacks and barriers, including lapse and relapse. Although it is defined as a 'person-centred' journey, people in recovery must also have a network of allies to keep them focused on the road ahead; the contribution of families, friends, social workers, support groups and healthcare professionals all help toward improved recovery outcomes.[10]

Outcomes for drug users improve when their family is behind them; they are more likely to start treatment, more likely to complete their course, and more likely to maintain their new lifestyle afterwards. Clinical guidance states that families and carers are a valuable resource in drug treatment and can be involved wherever possible and agreed by the patient[11]; treatment charity Phoenix Futures, for example, found that half of their residential service users said that their mother was the main source of support in their recovery.

A person's ability to address problem drug use stems from a series of personal and environmental factors, including the range of skills or capabilities they may possess, the availability of resources and opportunities within their community and their access to, and relationships with, different networks in their social sphere – their family in particular. These factors are known as **'social'** or **'recovery' 'capital': *"the breadth and depth of internal and external resources that can be drawn upon to initiate and sustain recovery from alcohol and other drug problems."*[12]** Families and relationships are obviously key elements of this recovery capital.

"Social capital: the resource a person has from their relationships (e.g. family, partners, children, friends and peers). This includes both support received, and commitment and obligations resulting from relationships."[13]

Indeed, families are also intrinsic to many other elements of recovery capital including housing, money, values and beliefs. The support they can offer is vitally important and can significantly expand the choices, information and resources available to people as they attempt to overcome their addiction.

Brenda underlines how the ongoing support she provides is essential for her daughter's fragile recovery from heroin addiction:

"I know that if anything upset her ***I'd be there trying to talk with her*** because I know now that she could relapse."

{Lambeth}

"Gradually she started to go to meetings and rehab and we're coming through it now… she's training as a prison link worker now. It's all because of the support of her family not turning her away when people said, 'don't even let her in your house'. By helping her and ***making her see she has a life***, she's recovering."

{Lambeth}

If stigma isolates and alienates the family, this key source of recovery capital cannot be used to its full potential and the substance user's recovery journey can be made more difficult. Of course this in addition to the negative effects of stigma on families regardless of whether or not the substance user is engaged in treatment.

Even with drug recovery programmes in place for users to access, the tough decisions that may keep someone on track with their recovery are often made by close family members or friends.

Helen remembers reaching the end of her patience:

"You have to do things which are alien to you. I remember ***I had to throw him out in the snow***. As a mother you nurture your children you wouldn't want your child in the snow starving hungry, freezing, but you have to tell yourself you are doing it with good intentions."

{Lincoln}

"You don't know 'til you are in that situation what you will do, ***but he is my son***."

{Lambeth}

As well as supporting the overall recovery journey, families will also help people in recovery to access goods and services which they would be unable to get for themselves due to stigmatisation. Brian, for example, recalls how he could not even perform everyday tasks others take for granted:

"I walked into a local Express store and was told, in front of the whole queue, to ***get out as I was barred***. Even though I had never done anything wrong in that store, I had in others, and the manager recognised me from police photos that circulate in those 'Shopwatch' schemes. Blanket banning by supermarkets could quite easily lead to some damaging situations for people in recovery."

"When I moved area and went to replace my free bus pass, I was told by the local council that I couldn't: if you had 'substance misuse issues', you weren't allowed."

Brian's story illustrates how the mark of stigma and institutionalised discrimination can deny substance users simple opportunities to go about their lives, even those whose journey into recovery is well established. Often in these cases it is the supportive family who will have to step in. Was any thought given to the family of Brian when barring him from the supermarket? Should they also be penalised for his former drug dependency by having to take on everyday tasks on his behalf?

The importance of supporting families

"Stigma and discrimination inhibit families from accessing support, either for themselves or the drug user."[14]

> "My mum sought support and, in as quickly as two weeks, that support had a positive effect on my addiction and the way that it went. I was at a fork in my addiction, the right road or the wrong road. ***By my mum having support for herself, it made me more able to make the decision to go down the right road.***"[15]

Adfam has long called for the expansion and improvement of dedicated family and carer support services to address their needs independently of those of the substance user, as well as to help them fulfil a positive role in recovery should they choose to take it.[14] If the role of families in treatment is to meet its full potential then families need to have access to support for their own needs too.

Families' lives can be turned upside down in their attempt to maintain faith in the recovery journey, offering unconditional support at each setback when others have given up. Too often families are vulnerable and lack the knowledge and resilience to even begin supporting someone else's treatment without having their own needs met first.

> "Even if it's your own child, other family members or neighbours can make you feel very hurt, very depressed, and you're very stressed out already with the situation. ***By people not supporting you it makes it worse.*** You think it's something you did, you feel like a bit of a failure, like it's something to do with you."

With the help of specialised drug and alcohol services and support groups, families can begin to understand what being addicted really means and to learn why recovery is difficult. This gives families the strength to support their loved ones in getting back on their feet, and the determination, resilience and support structure to cope if they fall back. If families are not supported they are less able to cope with the chaotic day-to-day effects of a loved one's substance use and less likely to play a productive role in recovery; or, worse, they may hinder it.

> "There's often ***a lack of awareness and understanding*** amongst wider family and professionals about what is actually going on. They don't realise you are on a journey as well."
> {Newcastle}

Brenda explains how family relationships and a support group helped her stay strong for her daughter:

> "When others were saying only negative things, my other son and his wife were there to support me; the love of my son helped me get through a lot of the pain I was going through when I couldn't talk to nobody and that enabled me to help my daughter. It took me about two years to be able to come to a group like this, but I'm glad I've come 'cause I could talk to people… it was moral support I got from this group."
>
> {Lambeth}

Sustained recovery depends on a person's supportive network of people; family members are typically the backbone of this network whilst support services and other professionals also play a central role in mapping out the recovery path. For all individuals in that network, however, it is a long and often difficult process presenting countless obstacles and challenges, not least the stigma of being associated with addiction. It is a heavy burden to share and tests even the strongest of families; one cannot assume that just because the substance user has sought help, this is sufficient for the family to return to normal.

Debbie reflects on the stamina required to guide a drug dependent person on their recovery:

Support gives families the strength to make, and stand by, the difficult decisions they face every day. Stigma needs to be broken down so families feel comfortable coming out into the open and seeking the support that they need and deserve. In addition to improving their own quality of life, this support equips them with the tools they need to support their loved one's recovery, if that is what they choose to do.

> "You get great strength to support them in the end, but it takes a long time to get used to the idea of what's happened."
>
> {Lambeth}

As long as stigma persists, the goal of sustained recovery will remain out of reach for many substance users and their families.

Personal perspective

Steve Brinksman, SMMGP Clinical Lead and Birmingham GP

*"**GP's can provide support to the family** on the effects a relative's drug use is having upon the health of the family. They are also able to provide information on other types of support and services available, either for the family or for the drug user, and make referrals to other workers and agencies."*[16]

Continuity is the cornerstone of general practice and the long-term relationships that GP's have with their patients mean that, probably more than most health professionals, we are aware of the negative impact of stigma and the enduring damage it causes.

Many of my patients with drug and alcohol problems also have family members registered with our practice. These can be parents, siblings, partners and children or sometimes all of these. They are more likely to present with symptoms of stress, anxiety and depression and the stigma family members face is a major contributing factor. These stigmas can manifest themselves in a number of ways – either indirectly in their daily dealings with a family member who is experiencing distrust and prejudice or directly when people insinuate that the family of a drug or alcohol user must either be to blame or be responsible for their behaviour. I have had family members who have been subjected to a range of stresses from being shunned to direct verbal abuse. Others have become socially isolated in an attempt to avoid their family member's problem drug use becoming known.

The causes of addiction are complex and multifactorial. Ignorant oversimplification in this way only exacerbates the root problem. Whilst GP's are generally sensitive to these issues, regrettably stigma can occur anywhere, even within the health care professions, for example when the family of a drug dependent patient is removed from a GP's list by association.

One of the main predictors of recovery is having sufficient social (or recovery) capital. Strong family relationships comprise a major part of this. If we fail to address the stigma families experience and to provide them with the necessary support, we not only let them down but we potentially risk reducing their willingness or ability to actively engage and support their loved ones in the many and varied facets of their recovery journey.

GP's and other primary care professionals are in a key position to help families support their loved ones on their recovery journey.
By highlighting the problem of stigma in a family context, and suggesting ways of improving outcomes for the whole family – including the person at the centre – we are taking an important step in addressing an often neglected area of the drug treatment system.

Conclusions: what can we do to challenge stigma?

"The stigmatisation of people with drug problems has serious consequences for government policy… If we are serious about recovery and reintegration, ***we need to be serious about tackling stigma****."*[17]

In its latest Annual Review of its 2010 Drug Strategy, the Government reaffirmed its commitment to challenging the stigma associated with dependence which it recognises as a barrier to an individual's successful recovery.[18]

Stigma around drug addiction is widespread and can shroud not only the drug dependent or person in recovery in shame and secrecy but also all those who stand by them. Stigma isolates families, breaks down the strong bonds that support long-term recovery, and threatens the moral code and social justice of giving everyone – as an individual – a fair chance. It's time that we all – drug and alcohol users, their family networks, and the wider community – worked together to eliminate this barrier to a more tolerant society.

> "The power of stigma is that ***it makes you accept things quietly***, because to kick up a fuss would be to draw attention to yourself."
>
> {Brian}

It is this enforced silence that needs to be challenged. In short, reducing the stigma associated with substance use – especially those in recovery, whose real desire to change can be hampered by discrimination – would make families affected by it more likely to come forward and seek support. By improving their health, wellbeing and quality of life, and enabling their positive role in recovery, outcomes will surely be improved for drug and alcohol users and for society too.

Where can we start?

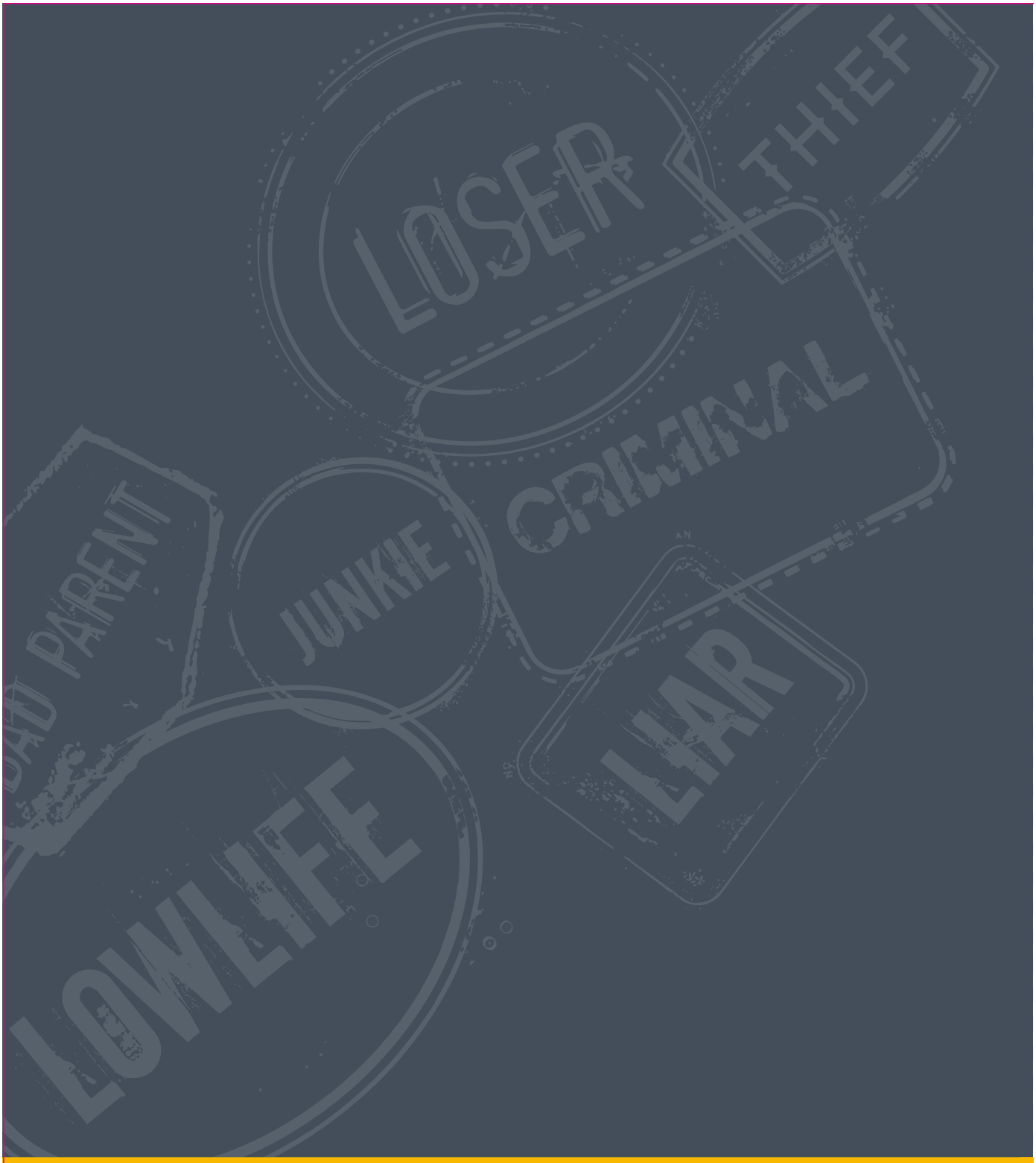
- Promote social inclusion and social justice for drug and alcohol users and their families by believing that recovery is possible for them as individuals, and by doing more to promote positive role models around drug dependence in the media.
- Highlight the damaging nature of stigma and discrimination on the families of people in recovery by talking about it, and expose people's negative attitudes and behaviours as shameful in themselves.
- Move away from criminalisation of the drug user to talking about drug addiction as a health issue.
- Provide a balance to media reporting of recovery and consider the family's perspective.
- Start the family recovery movement by educating our families about the nature, causes and consequences of addiction to promote acceptance and understanding of recovery.
- Encourage communities to interact with recovering drug users via local initiatives and volunteering groups to facilitate social inclusion, and in doing so focus on the whole person – not just the label of a 'problem drug user' – to break down discrimination through ignorance.

- Draw the attention of local councils and government towards the impact of stigma on families in order to secure financial support and guidance for individuals, groups and organisations involved in the whole family's recovery.

- Offer, as future employers, local businesses and neighbours, every opportunity to support people in changing their lives and help families get back to normal life.

References

1. Goffman, E., (1963) Stigma: Notes on the Management of Spoiled Identity
2. UK Drug Policy Commission (2009) Adult family members and carers of dependent drug users: prevalence, social cost, resource savings and treatment responses
3. Velleman and Templeton (2007) Understanding and modifying the impact of parents' substance misuse on children, Advances in Psychiatric Treatment 13:2
4. DrugScope/ICM poll (2009)
5. Adlaf. E.M. (2009) Adolescent stigma towards drug addiction: Effects of age and drug use behaviour, Addictive Behaviours 34:4
6. Corrigan P.W. et al (2009) The public stigma of mental illness and drug addiction: Findings from a stratified random sample, Journal of Social Work 9:2
7. Ronzani T.M. et al (2009) Stigmatization of alcohol and other drug users by primary care providers in Southeast Brazil, Social Science and Medicine 69:7
8. UK Drug Policy Commission (2010) Attitudes to Drug Dependence: Results from a Survey of People Living in Private Households in the UK
9. UKDPC (2009) Supporting the supporters: families of drug misusers
10. HM Government (2010) Drug Strategy 2010: Reducing demand, restricting supply, building recovery: supporting people to live a drug free life
11. HM Government (2007) Drug misuse and dependence: UK guidelines on clinical management
12. Granfield, R., and Cloud, W., (1999) Coming clean: Overcoming addiction without treatment
13. Best, D., and Laudet, A.B. (2010) The potential of recovery capital, Royal Society of Arts
14. Scottish Government, Effective Interventions Unit (2006) Supporting families and carers of drug users: A review
15. Adfam video: 'Putting it into words,' www.adfam.org.uk
16. Adfam (2010) Manifesto for families: 5 key challenges for supporting families affected by drug and alcohol use
17. UKDPC report (2010) Getting Serious About Stigma
18. HM Government (2012) Drug Strategy 2010: Reducing demand, restricting supply, building recovery: supporting people to live a drug free life – Annual Review



Challenging Stigma

Adfam
Families, drugs and alcohol